HAVING A CHILD WITH VELO-CARDIO-FACIAL-SYNDROME

Family adaptation to the disability through changes in parents' belief systems in families of children with Velo-cardio-facial-syndrome in Norway

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Spring 2012

II

Abstract

Background: There have been no reports of the world views, values and priorities of families of children with Velo-cardio-facial-syndrome in Norway, despite the fact that family beliefs are considered to be among the most important factors affecting the coping, resilience and adaptation of families to the disability.

Methods: Transcripts from two focus groups and written interviews (questionnaire) involving 16 families as key informants 32 parents of children with Velo-cardio-facial-syndrome were analyzed using qualitative methods. These families of children with Velo-cardio-facial syndrome had been invited by Frambu Resource Centre for Rare Disorders to attend a family one week course on Velo-cardio-facial-syndrome and it is during this period of one week that the research study was carried out.

Results: The themes indicated that raising a child with severe disabilities such as Velo-cardio-facial-syndrome can be a challenging and life-changing experience that spurs families to examine their belief systems. Parents can come to gain a sense of coherence and control through changes in their world views, values and priorities that involve redefinition of the child's situation and different ways of thinking about their child's disability, their parenting role, and the role of the family as a whole.

Although parents may grapple with lost dreams, over time positive adaptations may occur in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by the child to family members and the society as a whole. Parents' experiences indicate the importance of hope and seeing the possibilities that lie ahead of them.

Conclusions: The information of this study may be used to provide families with an advance understanding of the changes in beliefs that they might undergo which might lead to positive outcomes and family adaptation and may assist service providers in providing individualized and family-centered services and support to families.

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Acknowledgments

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Abbreviation/ Acronyms

VCFS – Velo Cardio Facial Syndrome

FRCD – Frambu Resource Centre for Rare Disorders

UiO - University of Olso

USA - United States of America

NSD - Norwegian Social Science Data Services

Key words

Velo-cardio-facial-syndrome

Family

Priorities

Values

World views

Qualitative

Families

Parents

Disability

Adaptation

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Tables of contents

1 Chapter one: Background information

1.1 Introduction

Families of children with chronic developmental conditions such as VCFS face many stressors but often adapt well to their situations (Summers et al. 1989; Van Riper et al. 1992). Adaptation is an ongoing, dynamic process occurring across the lifespan (Levinson, 1986), which involves shaping as well as adjusting to and being influenced by the world (Breines, 2004). Like individuals, families adapt and change over a period of time (Cowan, 1991).

Family belief systems are considered to be among the most important factors affecting the coping, adaptation and resilience of families (McCubbin, & McCubbin, 1993; Hewley, & Dehaan, 1996; Walsh, 1998). These belief systems are comprised of world views, values and priorities. World views are the family's assumptions about social and cultural environment, and their family's place in the world (Patterson, & Garwick, 1998).

Family values refer to the fundamental operating principles by which people conduct their lives and organize their family lives, such as the importance of open communication and of doing things together as a family (McCubbin, et al., 1993; Munoz, et al., 1999). Family priorities deal with activities and roles families feel that are most important.

To examine the evolving belief systems of families of children with severe disabilities, we took a developmental contextual (Lerner, 1998) and strengths based approach (Salebey, 1992). Such an approach emphasizes family strengths and focuses on understanding the changing relations between families and their life context over time.

Three areas of research are to our interest in changes in family beliefs over time. The literature on the coping and the resilience of individuals at risk, general family adaptation and resilience, the adaptation of families of children with severe disabilities are of great importance in this study. These publications show indicate the fundamental importance of belief systems in enabling people to create a sense of meaning and purpose in life and a sense of control over unfolding life events (Levinson, 1986; Cohler, 1987).

The literature on the resilience of individual families points to the need to understand how people acquire and maintain meaning that enables them to reframe events and experiences in an adaptive ways (Ruttter, 1993). Establishing a sense of coherence is considered to be a cornerstone of successful adaptation (Antonovsky, & Sourani, 1989; Olsson, and Hwang, 2002).

This literature also emphasizes the protective role played by beliefs, including spiritual beliefs and beliefs about self-efficacy, in reducing the risk for poor outcomes faced by individuals who experience various adversities (Garmezy, 1983; King, et al., 2003).

In the literature on family adaptation and resilience, family belief systems are thought to constitute the core of a family overall resilience (Hewley, & DeHaan, 1996; Walsh, 1998). They provide anchorage and stability, and a shared sense of meaning that help families pull together and face the future with a sense of strength (McCubbin, & McCubbin, 1986).

They also serve as cognitive maps that guide the choices of families make for their everyday activities (Rolland, 1993; Kumpfer, 1999). This literature provides information about factors affecting family adaptation, including factors related to world views and values, such as spirituality, connectedness and coherence (Oslon, et al., 1979; Stinnett, & DeFrain, 1985).

The literature on the adaptation of families of children with severe chronic health conditions indicates that these families cope by attributing positive meaning to their situations defining them as manageable, and making efforts to regain a sense of control (Summers, et al., 1989; Pettrson, 1991; Kazak, et al., 2004).

Parental reports indicate that raising a child with disability can spur families to examine their values and priorities in their attempt to settle on a view of their child's disability that makes sense to them and is confirmed by their daily experiences (Featherstone 1980; Scorge, & Sobsey, 2000). Over time, parents may experience changes in ways of seeing their child, themselves and the world. These new perspectives may encompass profound rewards, enrichments, and the appreciation of positive contribution made by people with disabilities as disability is not inability (Summers, et al. 1989; Scorge, & Scorgie, & Sobsey, 2000; Nelson, 2002).

A wide range of transformational or outcomes have been reported by parents of children with disabilities, including the development of personal qualities such as patience, love,

2

compassion and tolerance (Summers, et al., 1989; Behr, and Murphy, 1993; Scorgie, & Sobsey, 2000; Kausar et al., 2003);improved relationships with family members and others (Stainton, & Besser, 1998; Scorgie, & Sobsey, 2000; Poston, & Turnbull, 2004); an ability to focus on the present (Featherstone, 1980); and a greater appreciation of the small and simple things in life (Abbott, & Meredith, 1986; Kausar, et al., 2003).

Studies therefore indicate that, with time and experience, parents of children with disabilities may come to regain a sense of control over their circumstances and a sense of meaning of life by seeing the positive contribution of their children with respect to personal growth and learning what is important in life.

Aside from these changes in the world views, little is known about the meaning of a child's disability in the context of family life (Lawlor, and Mattingly, 1998), and how families may adapt to having a child with special needs by changing or adjusting their world views, values and priorities.

More specifically, little is known about the nature or extent of changes in belief systems that parents might undergo, the process and factors involved in these changes that is to say how they come about, the extent to which they are triggered by normative transitions in children's lives and whether different ways of thinking emerge over time that are of particular benefit to families and which may comprise unique paths to positive outcome and adaption.

Parents reports indicate that, over time, their child's disability may become part of their life's pattern rather than a dominant motif determining the meaning they give to their lives (Feartherstone, 1980; Shelton, and Stepanek, 1995), but this has not been explored in either qualitative or quantitative studies.

In general, studies provide information about family values or world views in the context of an emphasis on other aspects of family adaption, such as family coping strength for example (Summers, et al., 1989), family quality of life for example (Poston, and Turnbull, 2004), hope (Kausar, et al. 2003), or the characteristics of resilient families (Patterson, 1991). These studies also typically involve families of children with a range of disabilities, including syndromes, hearing and visual impairments, developmental delay, muscular dystrophy and autism.

In contrast, the objective of this study was to examine reported changes in belief systems of families of children with VCFS. The condition is thought to be prototypical of childhood developmental conditions and is examined to provide a point of comparison with other syndrome like Down syndrome (Turk, & Graham, 1997; Seltzer, et al., 2004) because VCFS differ with respect to time of recognition for example birth versus childhood and the nature of development features it often present.

Furthermore, in contrast, the focus of this study was on the common aspects of the experience of families of children with VCFS. Studies of parents of children with severe disabilities often examine outcomes such as parental stress or vulnerability to depression for example (Wolf, et al., 1989), and typically do not consider the positive contribution of the child to the family life, or the family's evolving life experience.

Studies tend to adopt a narrow perspective in which the child and in particular the child's diagnosis is viewed as the stressor that challenges parent's ability to cope and negatively influences their psychological well-being (Milgram, & Atzil, 1988; Konstantareas, & Homatidis, 1989; Tunali, & Power, 1993; Bromley, et al., 2004).

Parental coping and response styles are often viewed as traits that are independent from other circumstances and experiences that arise as a result of the child's disability. Parental characteristics such as hardiness, sense of control, and powerlessness may, however, evolve over time in response to specific experiences, such as interactions with the service delivery system in this case the family support system and the school system.

With respect to the belief systems of parents of children with severe conditions, Tunali and Power (2002) reported that parents of children with severe disabilities in comparison with other parents place more emphasis on the importance of spousal support and less emphasis on career success and other opinion of their child's behavior.

Van Riper and colleagues (1992) examined the well-being of families of children with special needs and found that many parents responded with adaptive functioning to the challenges associated with parenting their children. Studies have not explicitly examined changes in belief systems of families of children with severe health conditions.

Beyond studies of parents' experiences with initial diagnostic process (Howlin, and Moore, 1997; Midence, & O'Neill, 1999; Mansell, & Morris, 2004), we are not aware of studies

4

addressing how families of children with severe disabilities such as VCFS have navigated subsequent transition points and life experiences.

This study reports findings from a research investigation in changes in belief systems of parents of children with VCFS. The study consisted of one group involving key informants- parents of children with VCFS. The aim was to obtain information about the world views, values and priorities of these families, and how their beliefs might change over time towards positive family adaptation.

The study consisted of in-depth interviews with 16 families of both single- and two- parent families of children with VCFS from over Norway who were invited to Frambu Centre of Rare illnesses to attend a Parents' course on VCFS on the 08. June 2011. The findings of this study will be reported separately in latter chapters.

1.2 Theoretical framework

This study employed an integrative theoretical framework derived from family stress and coping theory (Lazarus & Folkman, 1984), the Family Adjustment and Adaptation Response, belief systems (Pettrson, 2002), and the family resilience framework (Walsh, 1998, 2003), to identify the specific components of family resilience as perceived by parents of children with severe disabilities such as VCFS.

The key contribution of the transactional model of stress, coping and family belief systems is the emphasis on the appraisal process. How an individual family perceives the stressor in the context of family available resources will influence the parent's adaptation process. The family adjustment and adaptation response model includes the examination of family risk and protective factors, and the shared family world views in the understanding how families can demonstrate resilience through successful adaptation to a range of stressor events.

 This framework identifies resilience as positive family adaptation with in the context of significant adversity. Family resilience theory identifies the key processes that are necessary for families to undertake in order to arrive at a state of adaptation. There are a number of similarities between theories of family resilience, belief systems, stress, and family adjustment and adaptation framework model that suggests potential for integration. First and fore most, each recognize the family as the unit of analysis. As such they acknowledge the

interactional components between individual family members as well as between the family and the community as a whole. Secondly each acknowledges that families will be exposed to a variety of normative or non-normative stressors throughout the family life cycle. The family's ability to adapt or emerge strengthened from their experience will vary as a function of family-based relational processes.

These processes include family functioning variables of flexibility and cohesion, family belief systems, or meaning-making processes, the importance of social, economic, and environmental contributions to the family's well-being, and the necessity to understand family adaptation and resilience as a process that occur over a period of time.

The advantage to utilizing an integration of models is that they each provide guidance as to the specific components that constitute family resilience. Furthermore, they each offer an empowering and respectful approach to understanding family resilience by emphasizing family strengths, abilities, and meaning-making systems as the keys to positive adaptation. They represent, therefore, paradigmatic shifts in how parents of children with VCFS are conceptualized and the nature of a child with severe illnesses such as VCFS.

2 Chapter two: Velo-cardio-facial-syndrome

2.1 Introduction

Velo-cardio-facial-syndrome is the most common contiguous gene syndrome in humans. The pleiotropic effects of this highly variable disorder results in anomalies in nearly every body structure and function and this involves the heart, face, plate and vasculature in the large majority of affected individuals. Behavioral abnormalities, including learning disabilities and psychiatric symptoms, are common. Velo-cardio-facial syndrome is caused by a micro-deletion of chromosome 22q11.2 (Shprintzen, 1984).

There have been no studies to confirm the birth prevalence of Velo-cardio-facial-syndrome, but estimates of the population incidence have been made. In part there is a problem in calculating the prevalence because the condition goes under multiple names, including: 22q11.2, Takao Syndrome, CATCH 22, DiGeorge syndrome, VCFS (Velo-Cardio-facial Syndrome/ Shprintzen Syndrome), Opitz G/BBB Syndrome, Conotruncal Anomaly Face Syndrome (CTAF) and Velo-Pharyngeal Insufficiency (VPI) among others. However, in this study, this condition will only be referred to as Velo- Cardio Facial Syndrome (VCFS).

Velo-Cardio-facial Syndrome (VCFS) was originally discovered by Doctor Angelo DiGeorge in 1965 now a retired endocrinology doctor at St. Christopher's Hospital for Children in Philadelphia, in the United States of America (USA) (Scambler, 1996). He did the first diagnosis of a collection of findings associated with VCFS in the 1960's (Shprintzen, 1984). VCFS is a complex disorder associated with a wide variety of symptoms that appear at birth.

It is estimated that there over 180 clinical features both physical and developmental that have been reported in VCFS (Shprintzen, 1984). They are often referred to as congenital defects implying that one is born with those defects. The underlying cause of VCFS is generally a missing piece of genetic information and to be specific it is chromosome 22q11.2 which is deleted thus the name 22q11.2 deletion.

His findings of VCFS were complex heart problems and a lack of thymus gland which were noted during post mortem. Later on, Dr Robert Shprintzen, a speech pathologist from Syracuse, New Jersey referred Velo-cardio-facial syndrome to the collection of findings made in patients who had problems with their soft palate (velum), heart (cardiac), along with characteristic facial features.

It is generally not known why this deletion occurs as the majority of patients who have a 22q11.2 deletion, which causes VCFS, do not have an affected parent therefore the change in the chromosome 22 is a "new mutation" in an individual.

 Only in about 10% of all cases is a parent also affected. There is nothing that either parent could have done before or during the pregnancy to have prevented the deletion from happening or could have done to have caused the deletion. This is a defect of the human race not of one particular person. It is therefore very vital to understand that this is no-one's "fault". The chromosome deletion was present in either the egg or sperm from which the baby was conceived.

VCFS is a rare genetic disorder which can cause severe body disabilities. It is the most frequently occurring chromosome deletion and the second most common cause of congenital heart defects. It is currently estimated that as many as 1 in 1,800 of the population may be affected by VCFS. International literature estimates that every 3-4000 born children have VCFS and it is also possible that 1-2000. Statistics in Norway shows that 15-20 children are born with VCFS every year.

There is no overview of how many people both children and adults have been diagnosed in Norway but a rough estimate is may be 150 persons. This is because there is very little known about VCFS and the little knowledge available is relatively new, and that is the reason to believe that many patients of VCFS have not yet got the right diagnosis.

Doctor Robert J. Shprintzen in his book management of Genetic Syndromes second edition states that "There have been no studies to confirm the birth prevalence of Velo-Cardio-facial Syndrome, but estimates of population incidence have been made. In part, there is a problem in calculating prevalence because the condition goes under multiple names" (Shprintzen, 2005). The other problem would be that VCFS is particularly very difficult to notice as often

the symptoms are mild or sometimes there are no obvious symptoms at all and the FISH test has only been commonly available in the last few years.

A syndrome is a collection of findings or symptoms that has been seen recurring over and over again in patients. VCFS patients can then have the following symptoms but please note that none of the symptoms occur in 100% frequency indicating no obligator features.

2.2 Most frequent noted anomalies

The heart

Cardiac defects, or congenital heart disease, are found in many patients with VCFS. In previous years this was the main feature of those cases diagnosed as genetic testing and detailed investigations were only triggered by a condition such as holes in the heart chambers. Not all heart defects require surgery, and if your child has not been diagnosed with a heart defect as a baby then it is unlikely that one will be found in later life.

The Immune System

In babies and young children the immune system is controlled by the thymus gland in the chest and sometimes this can be partially or completely absent or just not work well. Again the symptoms can be mild or severe. Often children are just more susceptible to colds and viral infections and fungal infections such as thrush. (Shprintzen and Singer, 1992)

Growth and Feeding

Some babies with VCFS have early feeding and airway problems which is related to major cardiovascular malformations. Vascular ring, a right-side aorta impinges on the trachea or the oesophagus and other major vessel anomalies like the subclavian arteries which results in constriction of the oesophagus and the trachea.

As a result it causes nasal regurgitation of milk, vomiting due to hypotonia in the digesting truck which may also lead to chonical constipation where by small or large bowel may be less efficient than normal. Babies with DGS swallow a large amount of air during feeding because

of uncoordinated breathing and swallowing. This air becomes trapped in the stomach and, when expelled orally, may cause substantial vomiting. (Shprintzen and Singer, 1992)

Facial Features

The facial characteristics noted are often very subtle and only apparent when a group of children are together. For example small, low set ears are noted, but if your family has large ears then your child's ears may just be small for your family. Other features include: dark/ red rings under the eyes, long slender fingers, a slightly open mouthed expression, abundant scalp hair, a broad bridge of the nose, short stature, a small jaw and small or missing adenoids.

Development and Learning

Many children with VCFS will have some sort of learning difficulty and developmental delays. These are not the same in all VCFS children. Your child may have delays in learning to crawl, walk and often talk, in comparison to other children. This could be due to your child being very sick and spending time in hospital or be due to problems associated with the deletion such as poor motor skills, muscle tone and lack of co-ordination.

Some children will only have mild delays others will have more significant problems. Often children will have communication problems. This may be due to palate or ear problems, or due to problems with language comprehension. The areas of learning where children are most commonly noted to struggle are language skills, complex maths and higher cognitive processes such as abstract reasoning and problem solving.

They often have difficulty with time concepts, shape, colour and size. They can also have disorganised thinking and become obsessed with one topic or idea. It is frequently noted that the children have poor performance IQ compared to assessed IQ. This is often termed a "Non-Verbal Learning Disability" and is unusual in people without a VCFS.

 Most children will attend mainstream school but may need some classroom assistance or special needs lessons. It is vital that your child is monitored and that any signs of difficulty are identified early on and the appropriate intervention given. Whatever your child's difficulties there are ways of encouraging and supporting learning.

Behaviour

There are also common behavioural traits noted. These often include poor social skills in a peer group, immature or inappropriate behaviour patterns, hyperactivity, impulsiveness be overly gullible and suffer from mood swings. Children are often noted as having low self-esteem, lack confidence and perform better when one to one with an adult whom they are familiar and confident with rather than their peer group and they often 'give up' at the slightest set back. It should be noted that occasionally children may suffer from 'attention deficit disorder' or ADD and that medication such as Ritalin should not be given as it can cause an adverse reaction.

Calcium

Calcium is important to the body in the firing nerve endings and muscles. Some children will suffer with hypocalcaemia, or an inability to metabolise calcium. This can cause tetany or muscle spasms and in severe cases, seizures. It is important for your baby to have their calcium levels monitored. However it is unlikely that your child will develop hypocalcaemia in later childhood if they do not suffer from it as a small baby, though small numbers have reported on-set at puberty.

This problem is caused by anomalies of the parathyroid gland which produces a hormone called parathyroid hormone or PTH (this also runs with high serum phosphorous levels). Medication is given to keep calcium levels higher and it appears that most children will outgrow this problem after their first birthday. Growth may also be affected by differences in hormone levels and you can ask to be referred to an endocrinologist if you feel your child is affected in these ways.

The Palate

This is one of the most common areas where an anomaly is noted. The types of problems are very variable and can often be a combination of anomalies. You should ask for your child to be seen by a cleft palate team, a plastic surgeon or a speech therapist if you feel your child may be affected in this area. The hard and soft palate can be affected. Babies often have reflux

or vomiting through the nose, and older children have difficulty with chewing/ swallowing lumpier foods, and problems with speech. The need for speech therapy and/or surgery is quite common.

Hearing / Ears

75% of the individuals affected with DGS have a degree of sensorineural hearing loss, repeated ear infections and glue ear is not uncommon, which can lead to temporary hearing loss. This is important to investigate as hearing loss can impede speech development. Many of DGS children have speech problems. If your child suffers with ear infections then a review by specialist is recommended. Very occasionally patients will suffer from mental health problems such as bi-polar/manic depression. Specialist advice must be sought if a problem is suspected.

Kidneys

Occasionally problems with kidney abnormalities are encountered. These may be noted by frequent bladder infections and can be checked for by an abdominal ultrasound scan. It is highly un- likely that surgery will be required for any abnormalities found.

Leg Pains

Many children have clubbed feet and suffer leg pains and cramps during the night or on resting from exercise. This can be due to tight ligaments in the legs or abnormalities of the foot or ankle joints. However, not every child with DGS will have every feature of the syndrome and the severity of the features will vary between children.

This means that no case of VCFS is the same thus making it difficult to make groups of the affected child and the family because all have different needs. Parents are also affected differently depending on the degree of the abnormalities and when the child is diagnosed (Shprintzen & Singer, 1992).

Velo-cardio-facial-syndrome diagnosis

In addition to a prenatal history, complete medical and family history, and a physical examination, in Norway it was not possible to know that one had VCFS before the FISH test was introduced in 1993. But now it has also come a new test called Multiplex Ligation Probe Amplification (MLPA) which can detect genetic syndromes and it is even cheaper than the FISH test Diagnostic procedures for DGS may include:

 Blood tests and tests to examine for immune system problems **X-ray -** a diagnostic test which uses invisible electromagnetic energy beams to produce images of internal tissues, bones, and organs onto film.

Echocardiography - a procedure that evaluates the structure and function of the heart by using sound waves recorded on an electronic sensor that produce a moving picture of the heart and heart valves.

Fluorescence in Situ hybridization (FISH) studies - when features of conotruncal heart defects, clefting, other facial features, hypocalcemia, and absent thymus are identified, a blood test is usually ordered to look for a deletion in the chromosome 22q11.2 region. FISH is specifically designed to look for small groups of genes that are deleted.

If the FISH test finds no deletion in the 22q11.2 region and the features of VCFS are still strongly suggestive, then a full chromosome study is usually performed to look for other chromosome defects that have been associated with this syndrome.

When VCFS is detected in a child, then both parents are offered the FISH test to see if this deletion is inherited. In approximately 10 percent of families, the deletion has been inherited from one of the parents. Any individual who has VCFS has a 50 percent chance, with each pregnancy, of passing it on to her or his offspring.

3 Chapter three: The study

3.1 A qualitative investigation

This study is a fulfillment of the Master of Philosophy in Special Needs Education, Department of Special Needs Education, Faculty of Educational Seinces, University of Oslo. The research described in this study focused on the 16 families from all over Norway of parents of children with VCFS who were involved in parent's course on VCFS on the 8th June 2011 at Frambu Resource Centre for Rare Disorders. Families whose children had been diagnosed of VCFS and the study targeted both single and two-parent families.

The families spent seven days at Frambu and all the families had with them the siblings who spent all those days going to Frambu schools and kindergartens. The study consisted individual interviews using a questionnaire as the tool for collecting data and means of exploring parent's experiences in the context of having a child with severe disabilities in-depth, within a longitudinal framework.

The interview guide was sufficiently detailed to allow for a focus response using the integration of family stress, the family adjustment and adaptation framework and family resilience theoretical frameworks. Questions were developed with view towards exploring family needs, resources, changing family belief systems and strength but sufficiently open to allow for examination of emerging themes and contrasts.

The questionnaire started with the question of how they came to know about VCFS and subsequently introduce questions of what is it like to be a parent of a child with disability. The questions focused on identification of the specific tasks and challenges parents encountered at each phase, the individual and family strengths that have assisted them in meeting them challenges, their description of the supports and resources that they found helpful, and the description of their current situation compared to the time the family entered the family support system.

Dependent on the information given on the question paper, the researcher asked for clarification of descriptions of incidents or time periods that were identified as particularly stressful, or particularly positive, using the benchmark of VCFS being a new and little known syndrome as the point of reference. In addition there a number of questions that asked the

participants to compare their experiences at the point of entry to the family' current situation. These questions were designed to elicit information regarding belief systems and family adaptation over a period time that may not have been directly in the earlier questions.

Data analysis was completed in three stages. The foundation of the first level of analysis consisted of classifying each questionnaire according to the components of the theoretical framework.

Analysis directive or deductive coding is driven by theory, and the goal is to "validate or extend conceptually a theoretical framework" (Hseih, & Shannon, 2005, p. 1281). This is to conceptually similar to temperate analysis (Grabtree, & Miller, 1992), which involves using a prior codebook developed from pre-determined concepts based on the existing theory.

In this study, the integration of family stress, the family adjustment and adaptation framework, and family resilience model formed the conceptual framework and provided the pre-determined categories of needs or risk status, protective factors and resources, meaning-making processes, and family adaptation.

The second level of analysis was completed using the constant comparative method of analysis (Glaser, 1965). The process produced 18 that were further analyzed to determine relationships that existed between them, resulting in different processes of change in belief systems that will be discussed in later chapters.

3.2 Study aims

The overall aim of this study was to explore and learn the family adaptation of parents of children with Velo-cardio-facial-syndrome in Norway within a longitudinal framework and to identify the individual, family, social, economic, and environmental factors that contribute towards family resilience and positive adaptation in this population.

To explore and learn family needs, strength and resources, identify parent's perceptions of what constitute s risk and protective factors.

To explore and learn how a change in belief systems can bring about practical initiatives that can able families to manage the care of their children in positive, respectful, and empowering and loveable way.

To explore and learn the experiences of parents of children with VCFS and the challenges they meet in the context of having a child with severe disabilities and being dependant on the social support system in Norway.

To explore and learn the nature or extent of changes in belief systems that parents of children with VCFS might undergo.

To explore and learn the processes and factors involved in these changes for example how they come about, the extent to which they are triggered by normative transitions of the children's lives.

To explore and learn if different ways of thinking that emerge over time might benefit parents of children with special needs again the resilience to positive outcomes and adaptation.

In general this stud had aims that consisted exploring and learning family values or world views in the context of an emphasis on others aspects of family adaptation such as family coping strength, family quality of life, hope and the characteristics of resilient families.

3.3 Study justification

The inspiration behind this study was by my own fathering experience of having a son with VCFS. The aim here is to highlight some of the factors that contribute to family resilience, coherence, coping and positive adaptation. I wanted to explore and learn, share knowledge and experiences with other families. Get to know their story, beliefs, perceptions, challenges and experiences in the context of being a parent of children with severe disabilities.

To explore and learn about world views of other parents in the same condition, the values, and priorities of these families and how their beliefs might change over time which in turn might lead to positive outcomes and quick adaptation.

To explore and learn other parents' views about their daily living situation, the challenges they face while searching for help and information in order to help their child. To learn about the kind of early intervention programs that they use and how they implement them. This is with a view to share knowledge and experiences with other parents and professionals in an attempt to gain insight into these private lives and yet all too often public issues.

By learning about changes of family belief systems of families of children with VCFS, I can introduce the personal narrative into an everyday working life for 'people whose work could be enhanced by this study, people like parents, doctors, nurses, social workers, administrators and teachers and policy makers.

It is not simply a matter of whether family needs are met, but rather the belief systems, the resilience of the families, coherence of the family, their coping strategies, parent's strength, resources available and the manner in which family needs are met. All those are likely to be enabling and empowering the families of children with VCFS thus a good life adaptation for both the child and the parents.

So it is of interest to learn how change in the belief systems of other parents in the same situation lead to adaptation to the ever increasing challenges of raising a child with severe disability. The way they perceive and experience the Social Support System and Early Intervention Programs in Norway and how they carry out their role as experts of their own child in relation to the world view was also of interest.

3.4 Study objectives

This thesis sets forth to explore the following objectives:

(i)   The changes in family belief systems of families of children with VCF, and how families change over time in their beliefs.

(ii)   The described family values, world views and priorities that lead positive outcomes and adaptation.

(iii)   Family perceptions, experiences, strength and needs and what brings about the changes in family belief systems.

(iv)   Family feelings, reflections, activities, their observation of other families and what they take to be the most important or wish for their child.

The investigator pursued his objectives in one qualitative study on families of children with VCFS through a one week fieldwork done at Frambu Resource Centre for Rare Functional Disorders with families of children with VCFS form all over Norway. Furthermore, the objectives are aspired through reviews of secondary sources and by studying the history of families of children with different disabilities that are developmental, physical and cognitive.

3.5 Families and disability

Naturally, a child's diagnosis of an illness or disability is considered a traumatic experience for all families (Wolfensberger & Menolascino, 1970; Blacher et al., 2002). Subsequent to the diagnosis, parents are thought to take a more negative view towards their child, and face increased stress with regards to their upbringing and the future (Kanner, 1953).

A wealth of research continues to suggest that families of children with disabilities such as VCFS face increased stressors (Blacher et al., 2005). Indeed levels of stress have been found to be higher in parents of children with special needs than in their typically developing counterparts, perhaps due to the ever increasing challenges and additional work of caring for a child with special needs.

Despite these stresses, it is apparent that certain parents and families are well adapted and appear resilient in the face of the challenges apparent. But given the diversity in adaptations seen in families of children with disabilities , there is need to identify these factors and processes, that lead to more resilient outcomes while other parents and families become increasing stressed over longer periods of time.

It has been previously suggested that family adaptation may be based on the interplay of experienced stress, available coping resources, changing belief systems, and ecological context in which an individual family must operate. Other conceptualizations have focused more directly on factors that may lead the perceived stress in families of children with disabilities, suggesting that the child's characteristics, social support, family belief systems, personal and family system recourses, and other life stressors may play an important role.

With notables of exceptions, few longitudinal studies exist that explore complex developmental processes detailing risk, resilience and adaptation in families of children with VCFS. Thus, the overall aim of this study is to examine trajectories of changes in family belief systems in families of children with VCFS, explore specific risk and compensatory factors that lead to more resilient patterns, positive outcomes and adaptation.

3.6 Research problem

This study is set to investigate the role of parents' belief systems in family adaptation process. The study has one main research question and three sub-questions. In this investigation, the research question is one of the first methodological steps that were taken while investigating the phenomenon of the study described as changes of parents' belief systems of families of children with VCFS.

The sub-questions were designed for the purpose of eliciting more information which could be used to answer the main-question fully. The main research question and the sub-questions are defined as follows below:

3.7 Main question

How do families of children with severe disabilities such as VCFS describe and talk about their world views, values, and priorities, how do these families change in their beliefs over time, what brings about these changes and how do these changes lead to family resilience, positive outcomes and adaptation for families in such conditions?

3.8 Sub-questions

In what situations do families of children with disabilities find themselves considering their values most and how does having a child with disability alter the family's perceptions of what matters and how does this experience make a family see the world differently?

What kind of discussions do families need to make and how might these discussions influence their world views, values, and priorities and how do they compare their experience at the point of entry to their current situation?

What are some of the situations that force these families to focus on their values, what do these families want or wish for their children in a long term and what particular periods do they define as particularly very stressful, or particularly very positive using the benchmark of the child's condition as the point of reference?

4 Chapter four

4.1 Research methodology and design

Introduction

In this chapter the methodological approach which was used to carry out the research will be discussed in details. This study sets forth an exploration on the changes in family belief systems and their effect on positive outcomes and adaptation of parents of children with VCFS. The study investigates and explores the experiences, values, coping strategies, family strength and the resilience of families of children with VCFS in Norway.

In order for the data to be collected, a well-suited methodology was employed in order to understand family resilience by emphasizing family strength, abilities, and meaning-making systems as the keys to the path of positive adaptation.

This chapter describes the design, methods and the procedures that were used as well as personal experiences encountered during the entire period of the field work. Research methodology is plan a researcher makes for selecting research sample, collect data and analyzing the data collected.

The plan should be easy and simple so that the results of the study can be easily interpreted and conclusions made. Given the nature of the topic changes in family belief systems of parents of children with VCFS, which has yet not had a significant attention in research, to understand its complexity the study adopted a methodology and a design that would provide a deeper understanding of the phenomena.

4.2 Qualitative approach and rationale

A qualitative approach is ideal for investing complex topics such as world views and for understanding continuity and changes in family development (Miles & Huberman, 1996; McCubbin et al., 1996; Walsh 1996). This study utilized a key informant approach, a qualitative method that allows an open-ended and detailed exploration of a topic (Marshall & Rossman, 1989).

Yin (1994) defines research design as an action plan for getting from point "A" to point "B", where "A" is the initial planning of the working title, subject and the set of questions to be answered, and then "B" would be the findings and some set of conclusions about the study.

In this journey between "A" and "B" there a number of major steps, including the collection and analyses of relevant data (Yin, 1994, p.19).

Furthermore, according to Gall, Gall, and Borg (2009), qualitative researchers aim to get an in-depth understanding thus the use of the qualitative approach. In this study, changes in family belief systems, experiences, values, priorities and the resilience of parents of children with VCFS in the adaption process were investigated in the context of having a child with severe disabilities or illnesses.

The choice of choosing a qualitative research approach is to provide a in-depth insight into the phenomena and also to provide a possible explanation and understanding as perceived by the informants whom were parents of children VCFS. As regard the design of the study, the researcher developed of the interview guide in form of a questionnaire in English and later translated into Norwegian.

 Thereafter, the written interview with parents, their answers to the questions where then translated from Norwegian into English prior to the process of data analysis. A selection of the sample site and the participants was made, and before the main field work a pilot study was done to test the instruments.

There was some adjustment made to the interview guide after the pilot study and finally the main interview guide was made. Analyses were made to the answers that were given by the different parents / parent. This study is an empirical enquiry that investigates contemporary phenomena within their real-life context, however, the boundaries between the phenomena

and context are not clearly evident and this is why the study relies on multiple sources of evidence.

This method involves an intuitive and reflective scrutiny of the sense-giving acts of consciousness but prior to their conceptual elaboration. It also indicates the process as involving a description of phenomena in the various modes in which they are present to consciousness (Gall, Gall, and Borg, 2009). The design also allows flexibility, as the phenomenon is investigated in its natural context and setting (Gall, Gall, & Borg, 2009).

This is supported by the field data collection guide: The qualitative research method allows flexibility for the researcher to probe further. The qualitative study has several advantages in that probing gives the respondents an opportunity to respond in their own words, other than forcing out responses. It uses open ended questions that have the ability to provoke meaningful and culturally salient responses coupled with unanticipated responses by the researchers. Finally, the method is rich and explanatory (Marshall, & Rossman, 1999).

The study actually focuses on the in-depth understanding of the phenomena in their context as a way to create more understanding the lives of families of children with severe disability. Empirical investigations and the use of other sources of data, taking into consideration its disadvantages as stated by Yin, who argues that designing and scoping a research work in order to ensure that the research questions are adequately answered can be difficult and data collection for many of research studies can be time-consuming and tedious.

Despite Yin's argument the study was still carried on as there is never a simple and easy job, at least not in the research world. The study involved selected families of children with VCFS in Norway. These families had particular instance of a phenomena and they were mostly selected because they all had children diagnosed with VCFS and were all going to participate in a family course on VCFS at Frambu Centre for Rare Diseases hence their selection for an this study.

The phenomena of the study are the changes in family belief systems and the resilience of families of children with VCFS in Norway. The main focus is to look at the adaption abilities of different individual families in a context of having a child with severe disabilities like VCFS.

During field study, one main method of data collection was used along side supportive methods. The main method included qualitative written interviews with a questionnaire that had to be answered by the all the families that wanted to participate in the study. Consultation of documents, field notes, and informal narratives where used as supportive methods.

Gall, Gall and Borg (1996) defines triangulations as a process of using multiple data-collection methods, data sources, analysis, or theories to check the validity of study findings. Triangulation helps to eliminate biases that might result from relying exclusively on any one data- collection method, sources, analyst, or theory (Gall, Gall, and Borg, 1996, p.574).

4.3 Method of data collection

The main research method which was used in collecting the data was the qualitative written interview with unstructured questions. Other supportive methods include: consultation of documents for guiding background information, field notes and informal narratives by the parents of children with VCFS themselves as additional sources.

4.4 About the study questionnaire

One of the most ubiquitous forms of human communication is by asking questions. Indeed, as implied in the Kipling quote, asking questions is perhaps second only to observation as the way people acquire knowledge. Technically a question communicates an inquiry. The question itself can be verbal or nonverbal and if verbal rhetorical or non-rhetorical.

This study used written questions and all questions took the form of an interrogative expression or sentences. All questions in the questionnaires were completely unstructured and this meant asking all study participants exactly the same questions in the same way in the same order.

Open-ended questions were used this is because there was no prior knowledge and answers to the question were not known. Furthermore, open-ended questions where used as they can generate ideas or obtain a fundamental understanding of the phenomena, issues or topic being investigated when relatively little is known about it.

They help to ensure that will not be unduly influenced by the presence of predetermined answers. Open-ended questions are imperative for obtaining information on certain kinds of variables for example unaided recall or top of mind awareness ("When you got to know that your child had VCFS what came on your mind first?"). Such questions require by definition the use of an open-ended question.

Open-ended questions were employed in this stud as they can help to monitor trends over time when unanticipated events may influence the answers that the study participants provide. An example if this study was about changes in public opinion about the Norwegian Social Support System over time one may employ more open-ended questions to ensure that public opinion can be captured no matter what events transpires.

4.5 Study interviews

Written interviews in form of questionnaires were employed by the interviewer with a clear specific purpose of obtaining research relevant information and focused on content specified by the research objectives of specific description. Interviews, according to Yin (1994), are one of the most important sources of obtaining required information in qualitative study method.

This method is very helpful because it gives the opportunity to the interviewer to clarify any question which is of doubt to the respondent and it can draw the attention of the respondent to the right direction if he or she goes off topic. The interview guides for this study were formulated using the research main question and sub questions as the main basis or the main foundation.

An unstructured interview guide with open-ended questions were used and the questionnaire as the main instrument for data collection. The questions were short but (Bounded) Continuous, where the respondents were presented with a continuous scale. They were few in number straight the point and that encouraged the respondents to answer the questions eagerly easily and within the given frame of time.

It was also advantageous because it helped to collect standard data across informants and of greater depth than what could be obtained from a structure interview. I also had an opportunity to listen to parents' tales about their experiences, beliefs and resilience towards

the adaptation process which is exactly the phenomena that was being investigated. This provided a chance to obtain more information to supplement the questionnaire.

An unstructured interview with a questionnaire as the main instrument of data collection has its own flaws in a research process. Taylor (1984) gave a detailed criticism of this method based on the idea that it does not provide first hand information on how people act in their daily life. Prior to this criticism, the method was still used as the main instrument of the study in order to find out an in-depth perspective of the nature and the extent of the changes in family belief systems, the processes and the factors involved in changes.

4.6 Document consultation

Consultation of documents was another supportive method which was use for the data collection process as addition to the main method. Yin, (1994) inserts that the fact that document consultation could provide other specific details to check and verify if the information from other sources is true. In this study, international documents, administrative documents, and other relevant documentations were reviewed.

The purpose of referring to these documents was to find out the international world views on the concept of experience, coping and the resilience of families of children with special needs during the adaptation process. Along side the background history of the families of severe disabilities and the Norwegian Support System.

Even though the consultation of documents as a source of data collection have proven its grounds, many critics are in doubt of its potentiality over the reliance on documents even the fact that VCFS is a new syndrome and there has not been much research done on about it. In such situations, the researcher may find it very hard to find the exact documents to consult.

 Yin, (1994) states that some of the documents might be deliberately blocked and this complicate the search even more. What ever the case, consulting already existing documents helps to build on the existing educational research it can be a stable source of information and can be reviewed several times for validity.

4.7 Field notes

Field notes were also another supportive method used along side the main method for data collection. This included information that could be seen while conducting the interview, difficulties encountered, and special comments were all noted down. Field notes was also used to investigate what could have been missed during the process of filling the questionnaire. Having spent a whole week day and night with these parents and their children in many different setting field notes were such an enriching source of information.

4.8 Focus groups

Focus group discussions with the parents about their experience and life with child with VCFS, was also another supportive method used in the field during the data collection. More valuable information was reviled by the parents during these discussions and story telling sessions that were meant for parents to tell their life stories to other parents. This was done in form of discussion in groups of four families. Based on their experiences different families narrated different stories and most of them depicted difficulties and other more positive outcomes and one would sense that all families had a great sense of hope.

5 Chapter five methodology and design

5.1 Sampling

The sample of this study consisted of portion, piece, or segment that was representative of a whole or an entity that is represented all families of children with VCFS in Norway. A purposeful sampling was used to select the participants. Gall, Gall and Borg (1996) write that the purpose of selecting the sample, or samples, is to develop a deeper understanding of the phenomenon being studied. In purposeful sampling the goal is to select cases that are likely to be 'information rich' with respect to the study (Gall, Gall, & Borg, 1996, p.217).

5.2 Participants

The participants in the focus group were 16 families which included 9 single families and 7 two-parent families. Both categories had a child with VCFS and that brings the total number of children with VCFS spectrum condition to 16 and 25 parents. The single-parent family category consisted of 1 father and 8 mothers. All families had siblings with them since this was a family course on VCFS. These families came from all over Norway.

Every year Frambu Resource Centre for Rare Disorders invites parents of children with VCFS to a family course with an aim of educating parents on the condition of their child. In a very careful selection exercise Frambu selects families from all regions of Norway thus making this sample representative. Once a family participates in a particular year, that family will never be selected again. Ethics approval was obtained from the Research Board of Frambu Resource Centre for Rare Disorders, Siggerud. All participants gave informed consent for their involvement in this study.

We used intensity sampling, a purposeful sampling strategy which involves recruiting participants who have in-depth knowledge and who intensely manifest the phenomenon of interest (Patton, 1990). Frambu Resource Centre for Rare assisted in the recruitment and organizing families in groups and receiving back the questionnaires.

Frambu Resource Centre for Rare Disorders was contacted by email and telephone and for permission to conduct this study at their centre and assistance to identify and contact knowledgeable (key informants) who were parents of children with VCFS that were coming to attend the family course on VCFS on the 08.06.2011. Frambu was asked to select families which had breadth of experiences, and had knowledge beyond their personal experiences, and were insightful and will to participate in this study, answer questions and talk about their experiences.

We provided information materials to Frambu to share with potential participants. A letter of request with information describing the nature of the study, the purpose of the focus groups, another letter of information and consent form from the Norwegian Social Science Data Services (NSD), and the confirmation of attendance form.

The letter of request stated that the focus groups would provide participants with an opportunity to share their experiences, opinions and ideas about families of children with development disabilities such as VCFS and how they think about life. Participants were then asked to fill in the confirmation of attendance and consent forms and to return these materials to Frambu where they were picked by the project co-coordinator.

This study gave extra attention to single-parent families as it would be of interest in future research to investigate the resilience of in single parents of children with severe disabilities such as VCFS in the context of single motherhood and childhood disability.

It is through that single family parenthood that creates additional stress that would further compound the issue of resilience and adaptation. Fortunately, none of the families declined to participate or dropped out during the session of the writing interview. All the 16 families that came to the VCFS course at Frambu the 8th of June 2011 participated.

On arrival the on the first day at the information meeting they were all reminded again asked whether they had all got the emails and materials about this study two weeks before and the reminder a week later and whether they still wanted to participate in the study and they all replied yes they wanted.

It was made very clear to all parents that participating in this study was voluntary and once that was done we started contacting the each individual family asking them whether they were willing to participate in this study for the third time just to be sure. A list of their names was

made and the dates were set for written interview. On the day of the written interview, both parents were given a booklet of the questionnaire and were asked to complete and after completion, they had return it to the reception office of Frambu Recourse Centre for Rare Disorders.

However, before the selected date for the written interviews all parents were prepared for the exercise ahead of them. They were divided in two groups which acted as focus groups and each group was involved in an information meeting that lasted for 2 hour and the purpose was to break down the content of the questionnaire and throw more light on the different terminologies used in the questionnaire as it will be explained on the procedure of the study below.

5.3 Procedure

All participants attended one of the two focus groups. Both focus group meetings were held at Frambu Resource Centre for Rare Disorders on different days. The general aim of the focus groups was to obtain information on about the belief systems of families of children with disabilities, and how these beliefs might change over time.

The specific objectives of the focus groups were:

To see if the topic of the study was an important one the participants that is to say a topic that made sense and was worthy an exploration.

To hear how parents articulated and described their world views, values and priorities so that we could ask question incase there were unclear answers given after the written interview.

To explore the nature of changes in parents' belief systems in a retrospective manner.

Each focus group lasted approximately for 2 hours with a break of 10 minutes in between and they were both conducted by the investigator himself. The parents in these focus groups share a lot of information relating their experiences with respect to world views, values and priorities. During these sessions the researcher audio-taped both sessions and took notes in the field-study note book and these were referred to as field notes.

Both focus groups started with introductions of the people and the study, giving information to the participants about the importance of the study and then the key terms were defined for

the participants. Family values were defined as operating principles by which people conduct their lives and organize the lives of their families. On the other hand, family priorities were defined as reflections underlying values and they might involve taking on certain roles in life, such as helping others through voluntary work or advocacy roles, or might involve everyday choices about family activities.

After that short but important study, the investigator shared his family experiences, and then general discussion ensued. The following questions were used to guide the discussion:

How do families of children disabilities talk about their world views, values, and priories?

In what situations do these families find themselves considering their values

How do families change over time in their beliefs and brings about these changes?

How does having a child with disability alter a family's perceptions of what matters and how does this experience make a family see the world differently?

What kind of discussions do families need to make and how might these discussions influence world views, values, and priorities?

What short of things do these families celebrate together whether big or small?

What situations force families to focus on their values?

Does having a child with disability teach families special lessons in life?

What do families want for their children in a long term?

During the discussion other more prompts were used to the address the nature of family beliefs, the events or experiences triggering changes in family beliefs, as well as lessons that these families may have learnt in living with such a condition. We also probed for thoughts and feelings of participants, their personal reflections, and their observation of other families.

5.4 Instruments and data collection

In this study, data is defined as the perception of the parents. Two methods of data collection were used and these included focus groups written interviews in form of a Questionnaire. The discussions in the focus groups were audio-taped using audio recording machines and written interviews were done by giving the participants the question booklets and ask them to complete them and return them to the project coordinator. The study employed the human person as the primary collection instrument, followed by note books, audio-tape machines and the questionnaire booklets as the main tool.

Focus groups were used as they are instrumental in gaining first-hand information from the respondents. The questionnaire was used a means of eliciting the feelings, beliefs, experiences, perceptions, or attitudes of individual families. As a data collecting instrument, it was open or unstructured. This was because Open or unrestricted form calls for free response from the respondent and allows for greater depth of response however, it could be difficult to interpret, tabulate, and summarize the data.

5.5 Pilot study

Before beginning on the full research project the researcher needed to know that his study was valid and that the study's design was able to capture the data he was looking for. Furthermore, he needed to know that the research he was planning to do was the most accurate and reliable research was possible. The best way to do this was to perform a pilot study.

A pilot, or feasibility study, is a small experiment designed to test logistics and gather information prior to a larger study, in order to improve the latter's quality and efficiency. A pilot study can reveal deficiencies in the design of a proposed experiment or procedure and these can then be addressed before time and resources are expended on large scale studies.

The instruments and the logistics in this study were first subject to a pilot study for the purposes described above before use in the main research project. The audio instruments for recording discussions in the focus groups and the questionnaires were earlier developed and tested at the Alternative and Supplementary Communication (ASC) course for parents of children with severe disabilities that was held on the 12.05.2011 at the Habilitating Centre for

Children in Hedmark–Hamar. Nine parents participated in this pilot study, 3 fathers and 6 mothers and all families had children with different severe disabilities.

5.6 Ethical issues

I had to take a lot of precautions as regards safeguarding the interests of the participants and the institutions. As part of the preparation for the study, I noted that the Data Field Guide as stated by Marschall and Rossman (1999) and Gall Gall and Borg (2009) were strong about researchers attending a professional course on ethics before embarking on any research. I resorted to a pilot study on the topic and ensured that I observed the relevant aspects spelled out, for my study.

This included respect for the participants; respect for the families; justice and beneficence (reducing any risks that could emerge during the study). I also took guidance from the Data Field Guide Marschall and Rossman (1999) and Gall, Gall, and Borg, (2009), regarding caution on collaborative relationships, fabrication of data and plagiarism.

So whatever information or data that was used ethical issues were acknowledged. This included seeking of formal consent from the Norwegian Social Science Data Services (NSD), parents, and Frambu Centre for Rare Disorders. The Authorities and the participants had to be given a clear plan and an over view of the intentions of the study.

This was done by repeatedly mentioning about the exact phenomena I was to investigate. Throughout the whole research period, I had to show my appreciation for the participants thanking them for their time after the exercise. It was very crucial for me to ask for consent of the participants and the administrators and workers at Frambu in order to create collaborative, cordial relationship thus observing issues and a favorable condition for my study. I finally had to assure them again that the data were purely for the study purposes.

5.7 Selection procedure of families

The reasons for choosing these families were that they were all had children with VCFS and were gathering at Frambu Resource Centre for Rare Disorders and that made it easy for me to meet them and their children. I also got a chance to spend a whole week with them. That also gave a chance to experience some of their daily life.

5.8 Selection of site (Frambu)

As mentioned earlier, the fieldwork was carried out at Frambu Resource Centre for Rare Disorders which is one of the many national competence centres for rare illnesses in Norway. Frambu is a state financed centre with a responsibility for about 100 different diagnoses and the centre is a supplement to the Norwegian ordinary social support system. It is also a meeting place for families and experts from many different fields. It offers support to parents, children, youth and other family members through out their lives.

Having a child yourself with rare and little know illness or get a child with a rare disability touches the whole family and the network around you. Frambu as centre for rare and little known diseases, collects, develops and saves information and knowledge about rare or little known diseases to persons with the diagnosis, parents and those working as experts in different environments and jobs.

The goal is that children, youths and adults with disabilities can live a life according to their own conditions, wishes and needs. Frambu conducts courses, guides children, youths and adults with rare disabilities. It also actively works to stimulate networking both locally and regionally there where people with rare disabilities live. Frambu maps out, gathers and systemizes the knowledge about the diagnosis in way that it can be used (www.frambu.no) accessed on the 08.01.2012.

5.9 Data analysis

Introduction

The trustworthiness of qualitative research generally is often questioned by positivists, perhaps because their concepts of validity and reliability cannot be addressed in the same way in naturalistic work. Nevertheless, several writers on research methods, notably Silverman, have demonstrated how qualitative researchers can incorporate measures that deal with these issues, and investigators such as Pitts have attempted to respond directly to the issues of validity and reliability in their own qualitative studies.

Many naturalistic investigators have, however, preferred to use different terminology to distance themselves from the positivist paradigm. One such author is Guba, who proposes four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study. By addressing similar issues, Guba's constructs correspond to the criteria employed by the positivist investigator:

i) Credibility (in preference to internal validity);

ii) Transferability (in preference to external validity/generalisability);

iii) Dependability (in preference to reliability);

iv) Confirmability (in preference to objectivity).

Although as recently as the mid 1990s Lincoln wrote that the whole area of qualitative inquiry was "still emerging and being defined", Guba's constructs have been accepted by many and this paper is using the same procedures as described above. The audio tapes of the focus groups were transcribed by the investigator, who thereafter, checked the transcripts to ensure accuracy.

The transcripts were then read through, noted relevant ideas and text segments, and he then made discussions on his observations with his supervisor about the main ideas over a number of times and reoccurring themes were finally identified. The goal for checking, reading the transcripts noting relevant ideas, discussions and observations was to develop themes that were representing a synthesis of the ideas generated by the researcher (Lincoln, 1995). The

rigor in this study was ensured by using procedures to address the credibility, dependability, confirmability and transferability of the findings (Lincoln, 1995).

5.10 Credibility

One of the key criteria addressed by the investigator of this study is that of internal validity, in which he seeks to ensure that his study measures or tests what is actually intended to be investigated. Being a qualitative research, the concept of credibility, deals with the question of how congruent are the findings with reality?

Lincoln and Guba (1985) argue that ensuring credibility is one of most important factors in establishing trustworthiness. The procedures used in this study to address the issue of credibility included triangulation of the data and member checking (Lincoln, & Guba, 1985).

Triangulation in this study involved the use of different methods, especially, focus groups and individual written interviews, which formed the major data collection strategies. Whilst focus groups and individual interviews suffer from some common methodological shortcomings since both are interviews of a kind, their distinct characteristics also result in individual strengths. According to Lincoln and Guba (1985), the use of different methods in concert compensates for their individual limitations and exploits their respective benefits.

Furthermore, in this study, supporting data was obtained from documents to provide a background to and help explain the attitudes and behavior of parents of children with disabilities, as well as to verify particular details that participants had supplied. Opportunities were also seized to examine any documents referred to by informants during the focus groups and the actual written interviews where these shed more light on the behavior of the families.

Another form of triangulation in this study involved the use of a wide range of informants for example fathers, mothers and both single-parented and two-parented families of children with VCFS. This was one way of triangulating via data sources. Here individual viewpoints and experiences can be verified against others and, ultimately, a rich picture of the attitudes, needs, values, priorities, beliefs or behavior of parents may be constructed based on the contributions of a range of people.

The exploitation of opportunities to check out bits of information across Informants, such corroboration may, for example, take the form of comparing the needs and information-seeking action described by one individual with those of others in a comparable position.

Triangulation via data sources involved the use of a diversity of informants, a range of documents were also employed as source materials. A methodological triangulation, which involves the convergence of data from multiple data collection sources and researcher-participant corroboration were employed in this study.

The data was triangulated with an aim of reducing bias and this was done by gathering information from parents of children with VCFS, holding two focus group meetings and using multiple analyses (Patton, 1990; Miles, & Huberman, 1994).

There were also frequent briefing meetings between the researcher and his superiors, such as a project director or steering group. Through discussion, the vision of the investigator was widened as others brought to bear their experiences and perceptions. Such collaborative sessions were used by the researcher to discuss alternative approaches, and others who are responsible for the work in a more supervisory capacity drew attention to flaws in the proposed course of action.

The meetings also provided a sounding board for the investigator to test his developing ideas and interpretations, and probing from others helped the researcher to recognize his or her own biases and preferences. The method of member checking is commonly used to ensure the validity of the themes emerging from qualitative analysis (Lincoln, & Guba, 1995). The member checks, which Guba and Lincoln consider the single most important provision that can be made to bolster a study's credibility were also used in this study.

Checks relating to the accuracy of the data took place "on the spot" during the course, and at the end, of the data collection dialogues. Informants were also asked to read the transcripts of dialogues in which they had participated. Here the emphasis was on whether the informants considered that their words matched with what they actually intended.

Another element of member checking involved verification of the investigator's emerging theories and inferences as these were formed during the dialogues. This strategy has been

employed by recommended by Miles and Huberman (19949). Where appropriate, participants may be asked if they can offer reasons for particular patterns observed by the researcher. The importance of developing such a formative understanding is ensuring trustworthiness in qualitative research.

Analysis and verification is something the researcher brought forth with him right away from the field and not something which he attended to later, or after the data were collected. When making sense of field data, the researcher did not simply accumulate information but regarded to what each bit of information represented in terms of its possible contextual meanings.

Thereafter, emails with a two-page summary attachment of the themes identified by the researcher were sent to all parents who participated in the study and asked them to provide feedback on the accuracy of the interpretations that were made. Parents were asked whether the themes made sense and whether they as people who participated in this study had any additional thoughts to share.

Furthermore, of the two copies of the summary that were sent to participants, they were again asked to jot notes, comments or reactions in between the lines of words and high light with red color and return by e-mail the marked up copy to the researcher's email address. The use of e-mail was preferred as opposed to ordinary post mail because it is cheap, saves time and does not involve other processes like scanning or faxing.

5.11 Dependability

Lincoln and Guba (1985) stress the close ties between credibility and dependability, arguing that, in practice, a demonstration of the former goes some distance in ensuring the latter. This may be achieved through the use of "overlapping methods", such as the focus group and individual interview. In order to address the dependability issue more directly, the processes within this study are reported in details, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results.

Thus, the research design is viewed as a "prototype model". Such in-depth coverage also allows the reader to assess the extent to which proper research practices have been followed. So as to enable readers of the research report to develop a thorough understanding of the methods and their effectiveness, the study included sections devoted to:

i) The research design and its implementation, describing what was planned and executed on a strategic level;

ii) The operational detail of data gathering, addressing the minutiae of what was done in the field;

iii) Reflective appraisal of the project, evaluating the effectiveness of the process of inquiry undertaken.

Furthermore, dependability of the findings was addressed by having supervisors from the University of Oslo read through it. Three parents of children with different disabilities one with Down syndrome and another with Rett syndrome and Velo-cardio facial-syndrome read the transcripts, discussed ideas and themes, and contributed to the synthesis of the ideas captured in the executive summary which was sent to the participants. These processes ensured that the data were free and did weigh to reflect any researcher's perspectives.

5.12 Confirmability

Patton (1990) associates objectivity in science with the use of instruments that are not dependent on human skill and perception. He recognizes, however, the difficulty of ensuring real objectivity, since, as even tests and questionnaires are designed by humans, the intrusion of the researcher's biases is inevitable.

The concept of confirmability is the qualitative investigator's comparable concern to objectivity. Here steps were taken to help ensure as far as possible that the study's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. The role of triangulation in promoting such confirmability was emphasized, in this context to reduce the effect of investigator bias.

Miles and Huberman (1994) consider that a key criterion for confirmability is the extent to which the researcher admits his or her own predispositions. To this end, beliefs underpinning decisions made and methods adopted are acknowledged within this research report, the reasons for favoring one approach when others could have been taken explained and weaknesses in the techniques actually employed are admitted.

In terms of results, preliminary theories that ultimately were not borne out by the data were also discussed. Much of the content in relation to these areas were derived from the ongoing "reflective commentary". Once more, detailed methodological description that enables the reader to determine how far the data and constructs emerging from it were accepted.

5.13 Transferability

Lincoln and Guba (1985), present an argument, and suggest that it is the responsibility of the investigator to ensure that sufficient contextual information about the fieldwork sites is provided to enable the reader to make such a transfer. They maintain that, since the researcher knows only the "sending context", he or she cannot make transferability inferences. However, in recent years such a stance has found favor with many qualitative researchers.

After perusing the description within the research report of the context in which the work was undertaken, readers must determine how far they can be confident in transferring to other situations the results and conclusions presented. However, it was important in this study that sufficient thick description of the phenomenon under investigation is provided. This was to allow readers to have a proper understanding of it, thereby enabling them to compare the instances of the phenomenon described in the research report with those that they have seen emerge in their situations.

Furthermore, transferability is not a crucial issue for qualitative studies (Maxwell, 1996). However, even though Maxwell made those remarks, transferability was enhanced in this study. This was done by inclusion of diverse participants with variety of characteristics that is to say mothers and fathers, single-parent and two-parent families of children with Velo-cardio-facial-syndrome.

6 Chapter six: Presentation of the results

6.1 Nature of family beliefs

The findings of this study focused on the changes in parentss' beliefs. However, to stage for the presentation of these findings, it important to first give a brief description of the nature of parentss' beliefs. Being a fundamental social group in all societies, all families have unique sets of beliefs, and families of children with disabilities are no exception. These families held diverse beliefs that are deeply embedded with in individual families.

Their world views encompassed seeing people's strengths, the goodness in every person, seeing differences and challenges as opportunities thus focusing on the positive contributions made by their children, the importance of being sensitive to the needs of others and seeing the children with the disabilities as unique members of the family, and not just children with disabilities, curses and burdens to the families.

The participants told the investigator about valuing life, happiness, achievements, the gift of love and making a contribution. Some families had laid aside some typical values for example, accomplishment and independence and instead these families took on and emphasized values of respect, acceptance, tolerance and co-operation.

They further emphasized the importance of a strong sense of family unity and commitment to one another; a high degree of interfamily support, which included emotional, social, and instrumental assistance; a commitment to "do whatever it takes" to survive each day and help others in the family function adequately; a commitment to keeping the entire family together including the their children with disabilities and a commitment to assure the highest possible quality of life for their children with disabilities

They also talked about their priorities and these among others paying bills, ensuring physical safety and security for all family members, advocating for their child with VCFS, promoting and encouraging the child's self-esteem, and doing things together as a family. It is against this backdrop of diverse family beliefs that a number of common themes emerged concerning

the role of beliefs in families' adaptation and the nature of changes in their beliefs over a period of time.

The findings of this study are presented in four sections consisting of themes accompanied by illustrative quotes:

(i)   Initial reactions to having a child with disabilities (a life changing experience and lost dreams)

(ii)   The adaptation process (being spurred to examine beliefs; the power and importance of hope; seeing possibilities ahead; gaining a sense of control and empowerment)

(iii) Changes in world views and values (stronger values, broader world views, areas of personal growth, and learning of what is important in life)

(iv)   Changes in priorities (giving up "trying to fix the child" and refocusing on the needs of all family members).

6.2 Initial common reactions to having a child with disability

This section of the initial common reactions of having a child with disabilities will first present a brief introduction explaining some of the initial common reactions that parents get before presenting the themes and the illustrative quotes from some of the participants which are under it.

On learning that their child has a disability, most parents react in many different ways that have been also shared by all other parents who have also been faced with the same disappointment and the enormous challenges of having a child with disabilities before them.

One of the first reactions is **denial** one of the parents in the focus group remarked as having said to herself and family, "This cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in breaking the news and providing the information about the child's problem.

Anger can also change communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: a mother said, "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one?

What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he have the capability of loving and living and laughing and doing all the things that we had planned?" she lamented.

Other factors like lack of sufficient knowledge and information about the illness also inspire fear. Parents fear that the child's condition will be very worse especially those that had a heart complications. Over the years, as the investor spoke to the participants during the discussions, there were many parents who said that their first thoughts were totally bleak.

One expected the worst. Memories return of persons with disabilities one has known. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether to have more children together, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Guilt concern about whether the parents themselves have caused the problem: "Did I do something wrong to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" Another parent said, "For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me.

Much self-reproach and remorse can stem from questioning the causes of the disability". Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?" many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked:

"What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship even when I believe in Him went to church almost every Sunday."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted.

You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value and belief system. This jolt to previous expectations can create reluctance to accept one's child s a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child, a feeling that many parents report at their deepest points of depression.

6.3 Themes and illustrative quotes under initial common reactions of having a child with disabilities

A life changing experience

This was a strong recurrent theme. One of the parents remarked: "Having a baby or a small child with a disability changes everything in a parent's life and family. It changed absolutely everything that we had take for granted in life. It was life changing. It altered our lives completely and also". Another parent stated: "Certainly I never in my wildest dreams had planned for any of the experiences that we have had since having a child with disability. It has changed absolutely every waking moment of our lives".

Lost dreams

The birth of a child with a disability, or the later diagnosis of a child's illness, sometimes required or led parents to give up hopes or expectations for their child's future, as well as the visions of themselves as parents. They lose out the touch with reality to accept life the way it is, to recognize that there are some things that we can change and other things that we cannot change:

> I needed to grieve for my lost dreams for this child, dreams as a mother for this child, dreams of academic excellence, dreams of marriage, and children as the chances of survival were minimal due to severe heart complications, dreams of self-sufficiency, dreams for recognition in the world as the world defines it, and not as we wanted to define it.

> I felt grief about my child's disability as no one seemed to have a solution to his condition. It was a sorrow for the pain and discomfort my child may have to experience; too much sadness for us because of the added stress on the family when a child has a disability; it was a sense of loss for what the child may not become.

Another parent described the impact of her son's diagnosis on her dreams of academic excellence for him and how this was related to feeling a lack of control:

I remember when I first got the diagnosis my preoccupation to be perfectly honest with you was only about me. It was not about my son. It was about what I was feeling at that particular moment. And I was feeling powerfully upset and disappointed about the diagnosis because it just completely turns your life upside down. I had plans.

I wanted my children to be happy but I wanted them to be accomplished. So both of us me and my husband had this plan and vision for our children as being academically keen. So to be confronted with the possibility that my son would have behavior problems, development problems and delays with very strange speech, I just did not what to do. I was totally devastated and I could not fix it.

For many parents of children with disabilities, lost dreams and the building and creating of new dreams are an integral part of grief. With a disability many of the dreams for the child and family are lost. Dreams may change; personal and family activities may be different, expectations for education may change, as well as many expectations for the future. It is difficult to have hopes and dreams lost and it is the reason we grieve.

We grieve for the child we thought we were going to have, we grieve for the opportunities that will never happen, and we grieve because the path for our child will not be as smooth as we had hoped. The challenge is to see hope, promise and value in the child, find acceptance and make meaning of a new life, find a new normal for a family and open the door for new hopes and dreams to emerge. It will take time, but the joys over the accomplishments of a child with a disability can be rich and fulfilling. There will still be dreams, just different ones.

7 Chapter seven

7.1 Family adaptation processes

We do not view grief as an obvious, overt phenomenon that is pathological and synonymous with distress and negative affect. Theoretically, we view grief adaptation to be a normal cognitive and emotional process. Cognitively, parents must come to understand the meanings and implications of the diagnosis for themselves and their child. They must accurately process information about their child and their child's condition.

Emotionally, parents must experience, accept, and express feelings of disappointment, sadness, grief, anger, and guilt that understandably may accompany the news that their child has a serious disability such as VCFS. Additionally, distressed parents must move past intense negative feelings to experience the pleasures, rewards, joys, and connection with their actual child.

 This does not mean that they will not feel distress about their child's condition, but that those feelings will not be as strong or preoccupying as they were initially. Many if not most parents who have a child with special needs will and do achieve resolution on their own and perhaps relatively quickly. However, we should not see it as a universal issue for all families.

Some families experienced a sense of continually adapting to changes. Their values and priorities seemed to change frequently also. Other participants mentioned that, although their priorities changed constantly, their family values did not change and they acknowledged the need to move on in their life.

7.2 Being spurred to examine beliefs

Having a child with disabilities can make families more aware of their beliefs. One of the parents who was a single-mother during the written interviews wrote about the birth experience of her child with Velo-cardio-facial-syndrome as something causing her to examine her values.

I think the very first thing that made really come to grips with my values was when I gave birth to my daughter who had VCFS with many severe symptoms such as clubbed feet, very

complicated heart problems, cleft palate and feeding problems. Having got all that information, that is when you started sorting out your really values, what is important and what do I focus on. And I think that is when I started thinking about it. As I regained my equilibrium and gained control, I also really started to think about my values and I meant by that.

A father talked about how events other than the child's birth or diagnosis can cause families to examine their world views and values:

My opinion is that families may engage in articulating or defining their values an event occurs. It may be a health related event or it may be school-related events where their expectations, say for the care of the child, do not mesh. So at that point they express their values, they articulate what is important for their child, and they try to often try to get that service or have their values system met.

For practical reasons it is very important for the parents to be clear about their values because these are linked to their priorities for their child thus the support and opportunities they seek for their child, the goals they have with respect to early intervention programs. The following quote indicates the importance of family values and priorities in driving their decisions about early interventions approaches to take.

I think that as families of children with disabilities, we have to be clear about on our values and priorities because we often have to present those priorities to professionals, to teachers, and some times even to family members and neighbors because we are often challenged on what those priorities are. Often people do not respect the fact that we know best and we are the experts on the conditions of our children.

So we have to be very clear about those priorities and, even though they change at times, we have to make those decisions. And if we do not make those decisions, we do not have clear choices for our children, and for our families. Then we are just nudged into what is out there and the world is taking control of the whole situation really. If we do not put our priorities straight then we do not get real choices.

Parents need to be able to articulate their priorities in order to provide a rationale for the decisions they often required to make:

50

We have sort of justified a lot of the decisions that we make. So we have to really be sure of our priorities and maybe that is the difference from some of our friends and families that we know. I think they have their priorities very straight but they do not always need to think about them or really clarify where they are going because they do not have other people make decisions for them in any way.

7.3 The power and importance of hope and of seeing future possibilities

Some participants expressed the power and the importance of hope and of being optimistic seeing future possibilities for the children and families mainly with respect to positive outcomes and opportunities for their children. Hope involves mental willpower and the way power that you have for your goals, having a vision for the future, which provides the family with a sense of direction in terms of the steps that can be taken to move forward.

Those possibilities hope also involves creating new dreams to replace those which are initially felt to be lost. One parent remarked how attending a Velo-cardio-facial-syndrome course at Frambu gave her family hope:

We came armed with hope that our child could have a normal life as possible and that was what was really important for us. We had and saw how people put philosophy into practice: here is what it takes, and here is what we are committed to doing. And it was like that is what we wanted for our children, and that is what we want.

Other parents are often crucial in providing this sense of hope:

What was really powerful for me was meeting other parents…who had really good positive attitudes and who had given their children lots and lots of different experiences that importance of meeting someone who is a little bit older, whose child is little bit older than yours and has done just great and wonderful things.

7.4 Gaining a sense of control and empowerment

Individuals play active role in constructing the meaning that their experiences hold for themselves, and the participants demonstrated that an essential component of resilience was their ability to control, manage, and create a positive meaning from difficult circumstances. Participants described the power that came from realizing they have choices about how they view their situations.

> At the beginning there is a lot of negativity that you let seep in because of the ignorance that you have about the situation, and because you have not had any experience at all. Then you get at a point where you gain that experience and, as you go on you realize that I do not have to let this come in between me and what I want. This is the world and I do make choices, and I am able of making choices I have the power I have the control.

Another parent tells a story of how she gained a sense of control and being competent parent by thinking about her child differently:

> I had the perception at that time that the whole future was laid out in front of me and it was very, very ugly… and it was something that I could not do anything about. And for about two years I cried whenever I was alone in the shower, the back yard, and public washrooms.

> And the single most abiding problem was that I thought I was ill equipped to do this…But I did meet a professional who did struck me in a positive way and that was the fortunate thing. She just said to me one day…" You know there is another way of looking at this". So she begun to model in terms of the language she spoke.

> Whenever she spoke about my son she would describe his behavior in a positive way and it was very clear to me that all you had to do is re-language something and it changed the way you experienced it….That is when the my crying stopped, when I suddenly realized that I could re-language it, could rethink this and it could result in a different experience…That is what advocacy and support is all about basically. It is about talking yourself…and other people out of thinking negatively about the experience of having the label disability.

7.5 Changes in world views and values

For most parents, a change in family beliefs is the first step to be taken to move towards seeking help and improving their adaptation. By emphasizing several family beliefs, families can start to gain positive energy which is needed to mobilize all resources towards a positive outcomes and adaptation. Changes in family world views and values can be the key in keeping parents engaged, and ultimately promote lasting improvements towards achieving healthy adaptation.

Values are central to parents developing a satisfying attachment with their child. Ideally, parents increasingly become able to learn to love, appreciate, and attach to their child. As these values are articulated, the child develops a secure attachment to the parents and become able to build new, more realistic dreams together. World views and family values, how they are articulated and promoted become key factors that influence parental adaptation

The themes in this section therefore, are describing family world views in a context of other ways of thinking about life and disability and the values that were strengthened, adopted or relinquished over a period of time.

7.6 Stronger values and broader world views

Some participants noted that values they had before having children, such as the importance of communication within a marriage or a home had become even more important. Parents remarked the increased understanding of societal issues:

"It is something which has opened a whole new world for us as well, a whole new world that we never ever would have known. We never ever would have known the problems and challenges that do exist, and we certainly understand them well enough now".

Another parent described the stronger values and broader world views that can emerge over time, noting that parents reflect on their journey up to this point, and they identify their strengths. They consider what their families have done well and the benefits of those experiences.

The shared stories of hope and progress that has come as a result of changed family world views and values. In the context of reminders of the unfolding nature of their child's

development and personality, parents begin to explore new dreams for their child and for themselves as parents.

I find that the majority of the families that I know who have kids with special needs are some of the strongest families that I've ever encountered….I remember someone making a comment once about "You must a lot of dysfunctional families".

I said it's the opposite, they are some of the healthiest….and strongest families that I've known"….And I think it broadened their world view….One of the things that I've always sensed is that the things that were of real value and importance before the child was born are still there and sometimes just evaluated more so….

I don't think that values change but I think the experience strengthen the values that were there before related to their view of their family and the future they look to for their family. I think initially a lot of battles are for their child and I think over time the battles become broader. They are not just fighting for their own child anymore they are fighting for all children with special needs. And I think it becomes a whole desire to improve for all kids, not just for their own child.

7.7 Areas of personal growth

Participants talked about the positive contributions made by their child. They gained a greater understanding for themselves through the experiences of raising a child with disabilities, and learned about patience, acceptance, tolerance, perseverance, compassion and unconditional love.

The innocence of a child with disability over 'the normal child' is outstanding. Having touched my life that way, he's made me a better person….I used to judge people for the way they looked, the way they acted. I was the type of a person that if you didn't like then I did like you. But no he's changed my life. He has opened my eyes. He would go and talk and hug anybody, whatever race, creed; whether you are ignorant to him or not, he will still say hi….hello. And I am blessed for that. I've a terrific child there a disability or not, I have a terrific child.

7.8 Learning of what is important in life

Parents noted many points and made many comments about how their experiences helped them to appreciate or value different things in life, including the small joys and accomplishments of their child, which might be taken for granted by other families.

It teaches you what is really important and some of the things that we miss in every day life because we so worried about all the big things. When my son was able to say or spell his name, or tell me our telephone number and where we live, that was something to celebrate. Whereas, to typical normal families that would just be 'Great, awesome' you know, 'You are doing great in school'. But to me ….you could say it was like winning a million crones in lotto.

Parents also mentioned the importance of respecting others, of love, acceptance, and inclusion, and of knowing the meaning of the worth of an individual.

Our children have taught us the true meaning of worth of an individual. Our society tends to value people according to performance, knowledge, education, the ability to earn an income. And these children have taught us that they have so many more inherently important values, which have shaped us as a family. We have then seen that as an opportunity. And other families can see, as a result of our children, that there are bigger and better values in society.

The different session of the focus groups parents told stories about the positive contributions made by their children with VCFS to others:

A teacher said to me: "Your daughter has made my class easy to teach". She said, "When your daughter walks in the class room, the competition is gone, the bickering is gone, the fighting is gone. She comes in and …. He brings love, he brings warmth and acceptance". And she said, "She taught us how to pray and sing before starting to eat, she is taught us how to love"….

I think back to 3 years ago when I was worried about would our children be accepted….would they be segregated, would it be called inclusion but in real sense isolation, would they be appreciated for who they are, would they be marginalized, would they be valued?

I was really worried about that….But just to see and I have parents coming up to me and "saying our kids are better because your kids are in their class; they come home and talk bout what your kids do, and they have become more sensitive to the needs of others".

7.9 Changes in Priorities

At times participants explicitly connected shifts in priorities to changes in world views, such as seeing children's strengths and transcending disability. Parents reported becoming much clearer on what mattered in life, and it was not about money, material wealth or power but an appreciation for relationships, happiness in the moment and celebrating the small things, and the redefinition of the whole situation of their child, an outlook that promotes resilience, positive outcome and adaptation.

7.10 Fixing or arresting the situation and not the child

Below are some of the quotes indicating that some parents gave up trying to fix the child as a priority and instead, opted to new ways of thinking about the disability. They adopted to strength, needs based perspectives which promote the flow of resources and support to the child and the whole family in response to the desires, wishes, and aspiration of the individual family.

They focus on what their child could do, rather than what their child could not accomplish. This can be considered a devaluing of the importance of achievement. It also involves a change in the parenting role from the role of supporting accomplishment to the role of loving and supporting the child to be happy.

Another thing which makes me feel I am smarter than I used to be is that I have given up trying to fix my son…..All I have to do is to figure out…..what he wants and what will make him happy, and try to put structure around it….He's fine the way he is and it was for me to figure that out and gee, the poor guy when I was figuring that out. And it's true that if you don't change the way I think about this child, if you always think that you wanted a normal child and you are always comparing your child to the normal child, you will never really be accepting and you just don't get anywhere. And I can remember with my daughter….I do not

know what we were doing but she just wasn't able to do it and I just thought it doesn't matter, you know. It really doesn't matter. She is still a little girl that I love and she can't do something, well, we'll go on to something different.

7.11 Refocusing on the needs of the other family members

There can be a shift over time in the centrality of the role played by the child with disabilities in the structure of the family life, reflecting a shift in priorities with respect to family activities and use of time and resources. At times, it is a struggle to balance the needs of other family members with the needs of the child with disabilities. Some parents indicated their priorities shifted to other children or their own growth and development.

So it's almost like….my priorities have gone to the other children because they kind of get lost, because you are so attuned to the disabled child. I think we are probably in many ways far closer than we would be had this not affected our family. We are certainly far more sensitive, I think, to each other.

We are probably sensitive in a fact to my older son who does not have a disability and his needs because we are so concentrated that he is going to get left out. One parent discussed how, over time, she reoriented her life to focus on her own needs and dreams. Dreams initially lost can be regained. I began to look at the fact that I had given up a lot of my dreams to focus on coping with my son's disability and that I didn't really have to do that. I can actually continue to pursue my dreams and now the focus for me is not coping with the disability but transcending it.

And it's so exciting. It is the most exciting thing in my life quite frankly right now. I feel quite embarrassed that I 'didn't' get it until now. Many study participants remarked that meeting other parents who had adapted and grown through similar situations helped them gain a sense of hope. "Optimism, having hope for the future, acceptance and appreciation" were described as ways of thinking that helped parents to adapt.

8 Chapter eight

8.1 Discussion

The study focused on the parents of children with Velo-cardio-facial-syndrome in Norway that were attending a parents' course on VCFS at Frambu Recourse Centre for Rare Disorders in June 2011. The study examined values, priorities, world views and family beliefs. It examined the role of changes in parent's beliefs on the positive outcomes and the adaptation process of families of children with VCFS.

During the focus group discussions parents shared their responses to the diagnosis, their patterns of adjustment, and their future concerns and expectations. In this way it sought to examine the family values and priorities that enable parents to function and to maintain their morale and optimism during crises and to be able to cope in a productive way with regard to both the present and the future of their child.

While striving to provide and mobilize resources that can meet the unique needs and desires of families of children with disabilities, one must take into account the range of values, priorities, world views and strengths represented in an individual family as part of the main factors that affect positive outcomes and adaptation.

The themes arising from this qualitative study analysis of the written interviews and focus group discussions involving key informants indicate that parenting children with disabilities can be an exceptionally rewarding experience characterized by challenges and triumphs. In addition to traditional parenting responsibilities, parents of children with disabilities must also fulfill the disability-related care giving needs of their children, prioritize the necessity to nurture themselves and meet their own needs and those of other family members.

 Parents of children with disabilities are more likely to experience major life events that can be life-changing experiences which can spur families to examine their beliefs, priorities and values. Parents can come to again a sense of coherence, resilience and control by redefining the situation of their child hence thinking differently about their child, their parenting role and the role of the family.

Although parents of children with disabilities such as VCFS may grapple with fear, denial, anxiety, guilty blame anger and lost dreams, it is believed that over a period of time positive outcomes and adaptations can occur. This could be in forms changed priorities or world views concerning life and disability, and realization of the positive contributions made by their child to the family, parents, and to community as a whole.

Parents indicated the importance of hope and seeing possibilities that lie ahead. The themes all together depict and show the importance of values, priorities and world views in the resilience, coping, and adaptation processes of families over time.

To a large degree, the findings of this study, which focused on the families of children with Velo-cardio-facial-syndrome, are similar to findings that are reported for families of children with a range of chronic conditions. This exemplifies and endorses the appropriateness of non-categorical approach to disability, in which there is an emphasis on commonalities in the issues and experiences of children and families (Pless, & Pinkerton, 1975).

Not surprisingly, there appear to be commonalities among all families with respect to general processes of adaptation (Pelchat, et al., 2003). As with all families, issues of control and creating coherent world views appear essential to positive outcomes and to a successful adaptation process.

Furthermore, in the following sections, the findings of this study are discussed in the context of the literature, focusing on two main themes of the study that is to say the influence of beliefs on the process of family adaptation, and the changes in world views, values and priorities reflecting redefinition of the child's situation or new ways of think about life, family and disability.

8.2 The role influence of beliefs on processes of family adaptation

As reported in the previous sections of this study, participants remarked that raising a child with a disability can be exceptionally hard and can be a life-changing experience. Most of the parents in this study indicated that in initial states of the child's disability, they tended to react in an emotionally and physiologically negative way to the diagnosis of their child's disability ('it opened my eyes and heart'). These results contribute to theories (Blacher, 1984; Marvin,

& Pianta, 1996; Seligman, & Darling, 1989) about parents' reactions when faced with a child with a disability.

These experiences may cause parents to examine their beliefs in ways encountered by others families. Raising a child with disability can heighten awareness of what is important in life, lead to changes in parents' and dreams, and alters the family's priorities and patterns of living (Gibson, 1999; Scorgie, & Sobsey, 2000).

Similarly, research involving adults with disabilities indicates major events can cause them to redefine what is important in life and adapt new ways of seeing the world, can make them more aware of their values, and can lead to changes in priorities and life goals (King et al., 2003).

We found that changes in family beliefs brought about significant changes in that family's social life. Many parents had to make changes in their social life initially of frustration and dissatisfaction to a more optimistic one. Research across lifespan indicates that self-understanding and other aspects of development are accelerated during the periods of instabilities and lack of equilibrium periods when people are challenged to develop new skills or come to new realization about themselves and the world (Breunlin, 1988).

Hope, spiritual beliefs, culture, routines, rituals and how we feel about life, death, and illnesses are important factors in people's ability to meet these life challenges. They have been found to be important protective factors for disadvantaged children, families, and adolescents (Masten, 1990) adults with disabilities (King et al., 2003) and parents of children with disability (Kausar et al., 2003; Poston, & Turnbull, 2004). This study extends the importance of hope to families of children with Velo-cardio-facial-syndrome.

As it is shown in other studies such as (Kazak et al., 2004), the this study indicates that changes in family belief systems enable parents of children with disabilities such as VCFS to gain a sense of coherence, meaning in life and resilience. In the initial stages of the child's disability parents reported feelings of lack of control and powerlessness. Kausar (2003) also reports that parents gained hope from other parents' experiences by seeing what others had done and achieved and by observing their attitudes, priorities and the ways they perceive the world and life around their child's disability.

8.3 Changes in world views, values and priorities

Participants reported various ways in which their beliefs had changed over time. These changes involved how parents thought about life, themselves, their family, and their child with a disability, and had implications for their behaviors and actions.

Even though families experienced considerable stress, as well as feelings of depression, anger, shocks denial, self-blame, guilt, or confusion. It would, nevertheless, incorrect to view such families as pathological because of their disabled child. It is then of greater benefit to examine the strong and positive relationships that develop between the parents and the situation of the child due to the change in priorities and world views.

A larger sample would undoubtedly provide a clearer picture of the parents' experiences and feelings, and significant differences between the families might then emerge. The findings of this study provide a greater understanding of the effect of changes in the parents' beliefs which promote love, hope, and strength for caring about the child and the rest of the family.

The changes in the world views of parents included;

(i)   Developing broader world views, trusting themselves and knowing that all families have existing strengths as well as the capacity become more competent.

(ii)   Redefining the situation of the child, seeing the positive contributions of their child in terms of personal growth and in learning what is important in life for example not taking things for granted, establish goals and new priorities and appreciating all small things in life, including small accomplishments.

(iii)   Seeing the child with the disability as a unique member of the family and not a burden or a curse to the family, building on strengths rather than correcting the weaknesses for example thinking about the child in positive terms, giving compliments and using positive language strategies and having it at the back of their heads that disability is not inability.

Parents expressed the need for a strong belief in the child and in the child's future, in maintaining an optimistic outlook along with a realistic view and acceptance of the situation.

62

They evinced their resilience from the holistic perspective "the importance of looking holistically at the child as part of the family, not as a separate entity," was noted by some parents. On the other hand, changes in family values included:

(i)   When starting to change your beliefs and values, parents remarked that it is important to understand where your beliefs and values originate and to address them at "their root." The key is changing your subconscious beliefs that one has about the family situation and the child's disability and identify core belies and strong values.

(ii)   Furthermore, devalue the importance of values like achievements and emphasize the idea of accepting the child, who "has the right to live like our other children, analyzing the situation in an objective way, and trying to obtain practical and efficient solutions.

(iii)   Focusing on other values such as appreciation of diversity, seeing differences as opportunities and the importance of unconditioned love.

The changes in priorities were so much related to changes in world views and values and these included:

(i)   Refocusing on the needs of the other family members and those of the parents themselves, mobilizing support and resources to respond to family desires, wishes and aspirations.

(ii)   Focusing on the promotion of family awareness of what it is and what is ought to thus responding to family concerns and needs.

The parents who participated in the current study were all at that stage when they have already accepted the full meaning and implications of the child's disability and had adapted themselves to it. Having achieved this realistic approach to such disability, they were able to function well, or at least adequately, within the family system.

These changes in family beliefs reflect the use of contextual reframing strategies, in which events and experiences are into a large or different perspective, or goals are adjusted to reflect situational constraints (Sandidge, & Ward, 1999). Reframing strategies that involve transcending events devaluing the importance of particular goals, and refocusing on priorities that can help families to establish a sense of coherence and control.

Reframing strategies also can have more concrete benefits and these can involve serving to change parents' expectations for themselves and for their children, validate their experiences as parents, and enable them to support and advocate for their children.(Cohn, 2001).

The redefinition and the changes in ways of thinking correspond to various processes and factors that have been found to be important in the adaptation processes of families and individuals. These factors and processes include the protective processes identifies as important for adults with disabilities for example replacing a loss with a gain or transcending, recognizing new things about the situation and oneself or self-understanding, and making decisions about relinquishing something in life or accommodation(King et al., 2003)

Furthermore, the fundamental ways of thinking related to family resilience, including making meaning from adversity, being optimistic and having a positive outlook, transcendence and spirituality, and religious beliefs (Bennett et al., 1996; Walsh, 1998).

The characteristics of resilient families, viewed as "the ability to bounce back or to return to a previous way of functioning" and the ability for the parents to balance the needs of the child and other competing family needs and attributing positive meanings to the situation (Patterson 1991).

8.4 Study implications for families of children with disabilities

The findings of the current study may provide families of children with disabilities with as sense of realistic hope for the future, and may validate their perspectives by showing that these families are not alone in their experiences and challenges. It may be beneficial for families of children with disabilities to know that family life changes, and that other parents report changes in their way of thinking about their child's situation and their parenting role that provides a sense of control and meaning in life.

It is very important for parents to know some of the characteristics which are used to attempt and operationalize family empowerment. The information in this study may help parents to gain access and control over the needed resources, decision-making, problem-solving abilities and the acquisition of instrumental behavior needed to interact effectively with others to procure family resources.

Parents may find it useful to know that it is common to feel a lack of control, disappointment, sadness, due to lost dreams. Over time, many families make or gain new dreams, develop new understanding of their child's disability and the world, manage life effective by redefining the situation, adjusting their priorities, and report life changing benefits for themselves, other family members, and the members of the extended or broader family or community.

8.5 Study implications for service providers and policy makers

The findings of this study have several implications for service providers and policy makers' understanding of family perspectives, making policies and providing services in a way that they are family needs centred (Rosenbaum et al., 1998). First, the findings inform both the policy makers and service providers about the scope of family beliefs and indicate the importance, to families of having meaningful and coherent world views.

Both service providers and policy makers can use the information in this to better understand how family beliefs may change over time leading to positive outcomes and family adaptation. This understanding may foster the insight and empathy into the experiences of families of children with disabilities, allowing policy makers to make policies that will enhance family function and service providers to offer support in more sensitive ways (Kearney, 2001).

This information may help service providers to diverge from the common intervention practices that focus on the family as a whole unit and not on the individual family member as the unit of intervention. This by providing services in an empowering way to families and by this empowerment we mean family's ability to meet needs and achieve aspirations in a way that promotes a clear sense of interfamily mastery and control over important aspects of family functioning.

The reflection on this information may contribute to more respectful and more supportive care, which is an important aspect of family-needs-centred service delivery (Rosenbaum et al. 1998). Secondly, the findings indicate the importance of ascertaining the values, and priorities of each individual family, being aware of and considering these beliefs in the interactions with parents and other family members.

Effective family assessment, assistance and support involves the recognition of the importance of family values determining family priorities for goals and services (Beiley, & Simeonsson, 1998). As well, a family-needs-centred model of service delivery recognizes that families are different and unique, and emphases the importance of identifying needs, individualizing services to meet needs, accepting diversity, respecting and supporting families. All of these behaviors require a deep understanding of the family's beliefs systems and the adaptation processes.

Thirdly, service providers can inform parents of children with disabilities of these findings, using the word and concepts used by the parents in this study to articulate various aspects of their belief systems. In this way, service providers can facility meaningful dialogue with parents about their values and priorities, and their priorities with goals with respect to therapeutic and early intervention program for their child. This explicit consideration and exploration of parents' beliefs can be useful on multiple levels and in multiple ways. It can:

(i)   Provide family members with any opportunity to gain hope and feel less a lone in their experiences (Kearney, 2001).

(ii)   Create a joint perception of the family situation which acknowledge and incorporates the family's values and priorities and views these as strengths and resources that can be utilized.

(iii) Create a therapeutic alliance between family members and service providers (Maritin et al., 2000).

(iv)   Provide anticipatory guidance that helps families to consider and obtain the support and resources they may need to deal with challenges and obstacles ahead (Kearney, 2001). All these aspects are important for effective interventions.

An important aspect of social support is feeling understood and parents look for professionals for understanding as well as practical help (Featherstone, 1980) When policy makers and service providers are not able to understand the family's basic values, parents may feel very

dissatisfied (Rolland, 1993). By making good policies that emphasize family-needs-approach and service providers discuss the values and priorities with the families this can provide parents with a feeling of being understood and cared for.

Furthermore, understanding the values, priorities, desires and hopes of families both with respect to family life and intervention outcomes appear to be fundamental to providing services that minimize the likelihood of the success of the intervention program. According to Beiley and Simeonsson (1998), intervention strategies need to be adapted to individual family characteristics, beliefs and cultural styles. When all aspects of clinical interventions are tailored to an awareness of family beliefs, then families are involved and engaged in the intervention processes.

This reflects a basic service delivery principle which is that of the customization (King, 2003). Engaging families in the intervention processes is relies fundamentally on the service provider being able to forge or find a connection with the families, and understanding family beliefs is an integral part of this process. The extent to which goals are in connection or concert with family values and priority systems is thought to determine the degree of family acceptance of and follow through goals (Bailey, & Simeonsson, 1988).

The meta-analytic and qualitative research studies suggest the importance of designing intervention programs that are congruent with parents' general world views, their hopes and priorities with respect to treatment outcomes (Cohn et al., 2000; Wampold, 2001). Research on clinical expertise has shown that expert therapists are those who able to create and intervention atmosphere that engages the client or family, which plan interventions that make sense and manageable (King et al., 2005).

These studies further indicate that expert therapists work on short time goals that are meaningful to clients' everyday lives and reflect clients' values, priorities and as well they are guided by awareness of the broader longer-term goals and desires of families, which involve issues redefinition, adjustment and adaptation (King et al., 2005). Family needs should be met in a way that make a family more competent with respect to the disability so as to negotiate its course of development thus providing families with a opportunity to strengthened family functioning.

8.6 Study limitations, strengths and future research directions

This was a study for the fulfillment a master's degree in special needs education at the University of Oslo. The study of the role of parent's beliefs in family adaptation process of parents of children with Velo-cardio-facial-syndrome, designed to inform a more in-depth interview study. There are some limitations to this study just like any other study would be and these included the selection procedures and under-representativeness.

The selection of families while depending on Frambu Resource Centre for Rare Disorders' invitations to a family course of VCFS was still not as differentiated as the investigators would have liked. Each family of child with VCFS get one chance to attend this course and very year Frambu takes between 15-20 families.

Have contacts with the families of children with VCFS we had to compromise. All the communication prior to our meetings with parents had to go through Frambu. We were unable to locate and invite more families to participate in the current study because Frambu had a fixed number of families that could attend per year.

This may be due to the inherent difficulty in locating and contacting parents of children with disabilities, VCFS in particular. But a subsequent study should make the efforts to include a more complete range of all families of children with VCFS. Because of this difficulty in sampling, the study was limited to 16 families.

However, it is reasonable to assume that the more refined the families, the more precise the findings would be. For example, having a small sample would allow the investor to more accurately assess the role in changing in parents beliefs in the family adaptation process.

Furthermore, with respect to the confidence used in describing the nature of changes in family beliefs, the study employed a retrospective approach and did not purposively recruit participants from a wide range of backgrounds. As the participants were the key informants with a wealth of experience, their perspectives may point to the strengths and adaptability of families to a greater degree than would be the perspectives of participants selected in other ways. Their experiences as knowledgeable individuals do however, indicate their ways of thinking that have practical benefits for others.

The method used to make conclusions in this study was triangulation of data. The investigator only used the data that was confirmed in the two stages of data collection that is to say focus groups and written interviews by the use of questionnaires. This method has been widely used and seen to enhance a study's generalizabilty and reliability (Rossman & Wilson, 1991). In addition, Lincoln & Guba (1995) stressed the importance of confirmability and this is why triangulated data was used in the result section.

The study looked at the role of changes in parents' beliefs of families of children with VFCS in Norway. Future research should attempt to uncover the prevalence of VCFS at birth in Norway and other countries and how many people have the diagnosis. Another attempt would be to uncover the stories of families raising children with VCFS in poor countries and poverty stricken homes. In many countries the voices of these families are often silenced.

A descriptive study of their situation is required to bring light to their issues and difficulties. The work of Arvystas & Shprintzen (1984) on VCFS and the works of Brickman et al., (1982); Dust, 1985; Hobbs et al., (1984) and Solomon, 1985 is of direct application in this area. It should be noted also that this investigation did isolate the type of the disorder. This is a limitation of the study. In the future the inclusion of other disabilities especially in terms of severity would be prudent.

Finally, there are two more limitations that need to be acknowledged and addressed regarding the present study. The first limitation concerns language which was yet another limiting factor to this study since I had to translate the questions form English to Norwegian. This barrier made it to formulate the questions the way I wanted as many words in English could not have their exact meaning in Norwegian.

As if that was not enough, the completed questionnaires and field notes were again supposed to be translated to English and this can lead to loss of some words. The second limitation has to do with time. The time frame for the whole field work was too short. More time was needed to spend with the parents to experience how their lives had changed.

9 Chapter nine

9.1 Conclusion

Many interesting factors contribute to positive outcomes and family adaptation processes, to able families develop the rhythmic and generative qualities of balanced and resilient families. It is therefore, more important to ascertain the factors and the processes associated with the successful adaptation of families of children with disabilities (LaGreca, 1991). If parents have failed or struggling to redefine the child's situation, failing to change their beliefs, values priorities, world views, and thinking totally differently and positive about the child's disability, there is little time and energy to be reflective on the child's situation or establish meaningful priorities, values, rituals and routines.

This initial exploration of the beliefs systems of families of children with VCFS has provided has provided rich insights into the roles played by world views, values and priorities in family adaptation process. It points to the resilience of families, the adaptiveness of their belief systems, and the utility of various reframing strategies in creating new ways of viewing the world, the family and the child. The world views reported by families include adapting a strength and family–needs-approach to helping their child, and realizing that is a unique member of the family not a burden and makes positive contributions to the family, community, the world at large and therefore is of value to the whole world.

The information in this study provides families with an understanding of changes in beliefs that parents and other family members might undergo, may assist policy makers in making realistic and good policies regarding families of children with disabilities and may assist service providers in providing individualized, family-needs-centred services that promote family resilience. This can be done by providing families with broad, normalizing understanding of their situations, hope and a sense of love, meaning and control. This should further emphasize that parents have the rightful role in deciding what is important for themselves and their family, and that the family and the family alone bears the responsibility for deciding its cource of development to the extent that the well-being and rights of all family members are protected. The role of service provided then must be to support and strengthen the family's ability to nature and promote the development of its members in a way that is both enabling and empowering.

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11 Appendix

11.1 Attachment 1: Interview guide (questionnaire)

The role of parents' belief changes in family adaptation process of families fo children withVelo-cardio-facial-syndrome in Norway

Gender...................Marital Status.....................

When did you first hear about Velo-cardio-facial-syndrome?

How did you get to know that your child had Velo-cardio-facial-syndrome and how old was your child?

What was your first reaction on getting the news about the diagnosis?

What motivates you and keeps you going despite of your child's disability?

What gives you the most pressure and stress and how do you cope with the situation and does this increase or reduce your worries?

How did you start to give thought to all your belief system?

How do you describe and talk about their world views, values, and priorities?

How do changes in your beliefs help you get adapted over time?

How do these changes come about and how do they lead to family resilience, positive outcomes and adaptation?

In what situations do you find yourselves considering your values most?

How does having a child with disability altered your perceptions of what matters and most important in life?

How does this experience make your family see the world differently?

What kind of discussions does your family needs to make and how might these discussions influence their world views, values, and priorities?

How do they compare your experience at the point of entry to your current situation?

What are some of the situations that force you to focus on your values?

What do you wish for your child in a long term and what particular periods do they define as particularly very stressful, or particularly very positive using the benchmark of the child's condition as the point of reference?

What short of things do you celebrate together whether big or small?

Does having a child with disability teach you special lessons in life?

What makes you hopeful in your child's situation in a long term?

How do you create time to be a lone and take care of yourself?

Knowledge is Hope!

THANK YOU SO MUCH FOR YOUR PARTICIPATION!

11.2 Attachment 2: Location of Frambu resource centre for rare disorders

Frambu, Sandbakkv. 18, 1404 SIGGERUD,Ski

11.3 Attachment 3: Letter to parents

To all parents of children with Velo-cardio-facial-syndrome who are participating in VCFS course at Frambu in June 2011

Would you like to participate in a study about having a child with Velo-cardio-facial-syndrome?

My name is George Kitogo Sserunjgi. I am a father to a child with VCFS, and now I am studying a master's degree in special needs education at the University of Oslo. In my master's thesis, I would like to focus on Family adaptation to the disability through changes in parents' belief systems of families of children with VCFS. The thesis will be written with the help of a written interview and focus group discussions and Frambu has granted me permission to conduct both the written interviews and focus group discussions during your one week stay at Frambu at the course you will be taking part in.

The written interviews and the discussions will be in form of questions around family beliefs, values, world views, and priorities. I will also be staying at Frambu the whole week with you when the written interviews and focus group discussions will be conducted if you have any questions about the study. It calls for specific knowledge of how changes in parents' beliefs can lead to family adaptation and how do these changes take place. Your participation in this study will give important information which is of great use to both service providers and policy makers in designing intervention programs.

It is totally voluntary to participate in this study, all the information that you will give me will be treated with trust and confidence in my master's thesis. There is no confidential information or photos need. We shall use only numbers linked to each parent and if you decline to participate in the project, the number is deleted form the name list. The name list and the answers will be destroyed after the writing of the thesis at the end of the project in May, 2012. This study is approved by the Norwegian Social Science Data Services (NSD).

Those who would like to participate will get an agreement form where you sign that you would like to participate in this project. You will be served with questionnaire which you will be required to complete and participate in focus group discussions and all this will happy during your one week stay at Frambu in June.

11.4 Attachment 4: Agreement Form

I have read the information above and I would like to participate in this study: ''Family adaptation to disability through changes in parents' belief systems of families of children with VCFS in Norway''.

Name ……………………………………………………………

Place : ……………………………., Date...

…………………………………………………………….

      (Signature)

Telephone number………………………………………………………..

E-post: ……………………………………………………………..

Thank you for your time!
Best regards

George Kitogo Sserunjogi   Liv Inger Engevik

_____   _____

Student ved ISP, UiO   Stipendiat og veileder ved ISP, UiO
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This study is approved by the Norwegian Social Science Data Services (NSD) with reference number 26745.